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Humanising health research: how can this be person centred?

In recent years, following a number of high profile reports of health care failures (Francis, 2013; Gosport Independent Panel, 2018), there has been considerable interest concerning humanising nursing care and the nurse education to support this (Scammell et al. 2019). This requires all practitioners and students to reflect on the way we see the world and to try to step into the shoes of those we care for, looking at care experiences through their eyes as fellow human beings, not just care recipients. This does not sound difficult and is undoubtedly the aim of those who decide to take up nursing. However even with the best of intentions, in today's high-pressured, resource-stretched care environments (NHS 2019), it is easy to slip into seeing care as a set of tasks and down playing those things that make us feel human (Galvin and Todres, 2012), such as feeling valued, secure, dignified. Rightly the movement to place the **person** centre-stage, as opposed to treating them unintentionally perhaps as an object of care, has permeated all aspects of the care system including how we undertake health research. What should nurses look out for to judge if health research is humanised?

There has been a huge shift in the last decades in the way healthcare is managed; subconsciously care workers and members of society we will have been influenced by this. One move has been the drive for a more humanised approach. Care used to be profession-focused and organised; for example those living with dementia 30 years ago were viewed as incurable and housed in large institutions where fundamental needs were addressed, but largely on a production-line basis (Kitwood 1997) which was highly dehumanised. Over time a social movement became prominent that pressured for the humanisation of care (Morse 2012). In other words, the general public in particular began to demand that their relative was treated like a person as opposed to an incurable disease. This led to the closure of such institutions and a growth in care approaches that respected the person, regardless of the prognosis (Kitwood 1997).

This social movement also led to more humanised approaches to the way health research is carried out (Morse 2012). Much health research is undertaken, but in the past patients were treated as objects of research with non-user friendly information about the research study, its benefits and risks, how it was done or details about the results. Most research was quantitative, that is it counted responses, and was designed by scientists without consultation with those they were researching. Whilst the findings were useful, they often minimised accounts of patients' experiences. For example researchers might count how many patients reported less pain (quantitative research) following a treatment but ignore how the treatment make them feel (qualitative research). The growth of qualitative research approaches, that is collecting information about what is going on from the patient perspective, has helped address some shortcomings of solely quantitative studies. Another example is what it is like to have chemotherapy (qualitative research) versus how many patients survive one year post-treatment (quantitative research). Clearly both sets of findings are beneficial. The humanising research movement has made the use of both research approaches more common where appropriate and therefore the results more meaningful.

The outcome of this drive to humanise health research is the recognition that patients and the public must be involved in all aspects of the research process. After all they are the main beneficiaries. Nowadays for scientists to gain public funding for health research, they must demonstrate how service users have been involved at all stages,

from initial design to how the findings are shared in an easily understood way with all involved plus the wider community. There is evidence that patient and public involvement (PPI) has benefitted the research process; Brett et al (2012) conducted a systematic literature review which highlighted that PPI resulted in more user-focused research objectives, development of user-relevant research questions and user-friendly information for participants, recruitment approaches, and interpretation of the results for lay audiences including publication of results. Challenges remain to accommodate the needs of scientists as well as those of the service users but the principle is now embedded in health research.

Nurses and nurse students increasingly undertake or are involved with health research. At the very least they read research in their quest to ensure they are providing evidence-based care. It is our responsibility in judging the quality of research to consider the extent to which service users have been involved in its planning and the way it is carried out. Make a point of looking out for this; PPI should be made explicit in the information provided to participants being researched and in any publications that arise from research studies. Gone are the days when patients could be used without question by researchers even if the aim seemed highly beneficial. Humanised health research means genuine PPI involvement where service users are at the heart of the research process.

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Dr Janet Scammell, Associate Professor (Nursing), Bournemouth University